

CARING FOR THE CARER

Caring for someone with dementia can be an intensive, challenging and rewarding experience. It requires time and energy and can be a hard and demanding task. Therefore, it is vital that as a carer you look after your own health and wellbeing.

When you are caring for someone with dementia it is often hard to see how you could take time out for yourself. This information sheet looks at ways to help you, the carer, in your caring role.

Information

Get as much information about dementia as possible. Knowledge takes away the fear of the unknown, and helps you to face the reality.

- Speak to someone from your local Alzheimers organisation

- Read books and brochures

- Ask professionals and social service agencies

- Source reliable information from the internet

You may want to take part in the education programmes that are provided for carers in many areas. Being trained in the different approaches to the caring role can help to boost your self-esteem, significantly reduce your stress levels and increase your ability to cope. Contact your local Alzheimers organisation and enquire if carer education programmes are available in your area.

Ask for help

It can be easy for carers to underestimate their needs or fail to do anything about them or simply don't know where to turn for help. Seeking help early and using the support services available will enable you to continue caring at home for longer.

It is important that you seek help early. It is best not to wait until you are desperate or exhausted before you ask for help or an outside person or agency has to intervene because your situation has got to crisis point.

It is important that you do not try to manage alone. You are entitled to help from health professionals and social services and your local Alzheimers organisation or GP can help you access them. Family, friends and neighbours may offer to help. They really mean it, so

take up their offers. Think of ways to let them help with caring and explain exactly what you would like them to do. Be open with your family, friends, and neighbours and tell them the truth. Be clear and open about your expectations of family members.

Don't feel guilty about taking time off. Looking after someone with dementia 24 hours a day can be exhausting. Plan to take regular breaks i.e. some time each week to spend out of the caring role. These breaks may involve friends, family or outside agencies to allow you a rest for a few hours. The first few times may be difficult for both you and a person with dementia but it is often found that after a few times you will both become used to the routine.

Support groups

For many involved in caring, a support group is a great help. These groups can maintain your well-being and support you in your role as a carer. There's nothing like meeting with people who know exactly what you are going through. Contact your local Alzheimers organisation to find out details of support groups in your area. You don't have to be the full-time carer to access these support groups – they are often open to friends, neighbours, children and siblings.

Services

Your doctor is the first person you should contact if you are concerned about the person in your care or yourself. Experienced carers suggest that you need to be assertive and persistent with doctors who aren't immediately helpful. When visiting the doctor make a list of things that are difficult or bothering you so the doctor has a clear indication of your problems. Keep in regular contact with your GP and/or specialists as needs will change over time.

Services such as day programmes, respite care and home help can be accessed after a person with dementia has been assessed by someone from their local Needs Assessment team. You can contact your local Needs Assessment service directly or you can be referred by your GP or local Alzheimers organisation.

Day programmes

Day programmes can have two-fold benefit. They provide motivation and socialisation for people with dementia while providing respite for the carer. Day programmes

are provided in different facilities; some will be designed especially for people with dementia, others will be shared with people without memory loss. Enquire about suitable day programmes by contacting your Needs Assessment team or local Alzheimers organisation.

It may be difficult to introduce the idea of going to a day programme to a person with dementia as they may not see the need to go and may prefer to remain at home.

It can take time for a person with dementia to get used to a new environment and new people. Ask other people, such as your doctor, family and friends to provide encouragement and to reinforce the positive benefits. Attending a day programme may give you confidence that others can provide alternative care too. It may also prepare the person for their transition to residential care should the need arise. Begin by trying day care one day a week and increase this as the person gains confidence to attend.

Respite/sitter services

Short-term care for a person with dementia is known as respite care and this can be provided in the community or in a residential care facility. If a person with dementia can not be left alone, a "sitter" may be able to come and be with the person while you go out. Some Alzheimers organisations provide sitter services; contact your local organisation to see if this available in your area.

Use the time you have to yourself from day care, home care or respite to do something you want to do, rather than something you have to do. Take the time to meet up with friends, do your hobbies or just take the opportunity to have quality time to yourself.

Take care of yourself

It is important that you stay physically and emotionally healthy.

Eat a healthy, balanced diet – plenty of fresh vegetables and fruits; avoid large amounts of highly processed or high calorie food; take alcohol in moderation.

Try to get enough rest. If your sleep is disturbed at night, take opportunities to sleep whenever you can.

Keep in touch with family and friends. You deserve and need a social life outside your carer role.

Take time out to maintain your interests and hobbies. It is important that you still continue with the activities you enjoy. You have a right to follow your own interests outside of the caring role, and it is important that you do so.

Find ways to relax. Some people find that time spent in prayer, meditation, self-reflection or counselling can help boost morale. Walking is an excellent stress relief and very calming for a person with dementia. Try gardening to lift your mood and relieve nervous tension.

Be positive

Your attitude can make a difference to the way you feel. Try to focus on the good things and try to not think about the things a person with dementia can no longer do. Try to make every day count as there can still be times that are special and rewarding.

Daily routine

Establish a basic daily routine in the household and try to stick to it. Try to keep things as normal as possible; try not to treat the person like an invalid. It is important to retain a person with dementia's ability to carry on independently for as long as possible. This will help them retain some sense of dignity and usefulness. Encourage the person to use remaining skills to carry on with tasks they are still able to achieve.

One step at a time

You might find it easier to cope once you have adapted to taking one step at a time. Try to focus on what you are doing right now and don't worry about what has been or what will be. Don't worry about what has been yesterday. Yesterday has gone. You can't change it. Try also not to worry about tomorrow. Tomorrow will come anyway. You can deal with it later.

Further help

Your local Alzheimers organisation is able to provide support and information for carers. Contact your local organisation on 0800 004 001.

Carers New Zealand provides information, advocacy and support for family caregivers. www.carers.net.nz

Alzheimers New Zealand Information Sheet Twenty "Understanding your feelings – notes for carers" looks at some of the feelings you may experience.

Alzheimers New Zealand has a range of information sheets and booklets available for people with dementia, their carers, families and whānau. Alzheimers member organisations located throughout New Zealand provide a variety of services and support to all people affected by dementia. Contact your local organisation on freephone 0800 004 001.

This information sheet provides a general summary only of the subject matter covered and is not a substitute for informed professional advice. Any person with dementia or their carer or family/whānau should seek professional advice about any individual case. Alzheimers New Zealand is not be liable for any error or omission in this publication, as a result of negligence or otherwise. This information sheet was produced in March 2010.

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